

Empowerment in middle-aged people with diabetes: The importance of working relationships

Margaret Stubbs

Article points

1. The relationship between healthcare provider and the person with diabetes has a significant impact on the individual's blood glucose control.
2. Adherence is a challenge when dealing with people with diabetes in primary care.
3. There is a gap between the person with diabetes' view of diabetes and its seriousness and that of the healthcare provider.
4. The influence of health beliefs on self-management of diabetes is significant and needs to be addressed

Key words

- Patient understanding
- Health beliefs
- Middle-age

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Evidence suggests that the ability of people with diabetes to become empowered in their diabetes self management is enhanced by their relationship with their healthcare provider (Anderson et al, 1995). Other evidence points to a link between the information given and the degree to which an individual with diabetes follows a management programme (Frandsen and Kristensen, 2002). These studies and others recognise the place that lifestyle and behavioural factors play in chronic disease management (Glasgow, 1995; Bodenheimer 2005; Clark et al, 2004). The study presented here set out to investigate the viewpoint of middle-aged men and women diagnosed with type 2 diabetes. Using semi-structured interviews the issues surrounding attitudes towards and the understanding of having type 2 diabetes were raised. Results revealed several factors that may encourage or hinder an individual's motivation to control their diabetes.

Chronic disease management is a constantly growing area in primary care and with the explosion of obesity in the UK the demands on primary care resources are set to increase even further (Barnett, 2004). The World Health Organization (WHO) has predicted that there will be a doubling of the number of people with diabetes between now and 2030 (WHO, 2007). It is therefore imperative that those involved in diabetes care within the primary care sector learn how to enable patient empowerment effectively from the time of diagnosis and understand how to overcome an

individual's barriers to self-management (Diabetes UK, 2005).

In the author's experience of working in primary care for more than 7 years with a growing involvement in the running of the diabetes clinic it has become apparent that factors exist (such as health beliefs, social support, relationship with healthcare professional) that can encourage or hinder people from taking control of their diabetes following diagnosis. In addition, during middle age (45–60 years), when the majority of type 2 diabetes cases are diagnosed, there may be extra demands in the form of elderly relatives

needing care, teenage children and possibly being at the peak of a career (Diabetes UK, 2005).

In their work with people of all ages with type 2 diabetes, the author and her colleagues have identified two distinct types of response to diagnosis.

- Those who either do not understand, or do not want to understand, what diabetes is and feel disinclined to do anything positive for themselves.
- Those who appear to grasp what diabetes is all about as well as the implications involved and consequently decide to take control of the condition.

Some people with diabetes appear to remain permanently in the first category, despite the best efforts of healthcare professionals. In the author's personal experience, the establishment of a good working relationship with a person with diabetes can enable them to feel empowered in their diabetes management. However, transition from the first category to the second tends to be very slow.

Aims of study

The aims of this study were to examine the attitudes of people towards lifestyle changes necessary following type 2 diabetes diagnosis; to explore the impact type 2 diabetes made on individuals and how they then approached the issue of control; and to understand what type of care people with diabetes are looking for and what will help them become empowered in the management of their condition.

Methods

Prior to initiating this study ethical approval was sought and obtained from the local ethics committee.

Qualitative interviews were chosen for this piece of research. Highly structured questionnaires were thought to prohibit free expression: they ask for a limited range of answers via tick boxes, are done in a very limited time period and do not provide an opportunity to communicate personal beliefs or values.

Focus groups could have been useful in generating greater freedom of speech and criticisms might therefore have been voiced

more freely (Pope and Mays, 1995). However, such an approach turned out to be impractical for the current study: there were considerable problems finding an appropriate place to meet undisturbed at a mutually conducive time. Due to constraints on the author's time an observational study was not feasible.

In order to try and unearth the beliefs and experiences of middle-aged people with diabetes in relation to management and understanding, the decision was made to carry out semi-structured interviews. These interviews were recorded with the participants' consent.

People with diabetes from a GP surgery not connected with the investigator's practice participated in the research following advice from an experienced medical researcher that unfamiliarity would generate greater honesty and openness about beliefs and experiences. Were the interviews conducted with people the author works regularly, the individual with diabetes might not have felt they could be completely honest about the level of care and advice they had received since diagnosis and may have withheld criticisms or concerns in case it affected their ongoing care. Additionally, people are more likely to assume 'sickness role' when talking with someone they know as a healthcare professional (Pope and Mays, 1995).

The lead GP for diabetes willingly assisted by taking responsibility for the searches necessary to identify people suitable for the study and to protect participants' confidentiality. He was also involved in sending out invitations to the potential participants. The aim was to have 20–30 interviews from which data could be retrieved. To keep the sample as homogeneous as possible recruitment was limited to people aged 45–60 years who had been diagnosed with type 2 diabetes less than 10 years previously. A shorter time following diagnosis would have enabled the sample to be more homogeneous, but in reality this would have yielded a smaller sample than was necessary.

The majority of the interviews took place in each participant's home in order for them to feel as relaxed as possible. The interviews were transcribed from the recordings. This allowed the interviewer to focus on the conversation

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1. Once conducted and transcribed the interviews were coded to link similar themes together using a computer software package.
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3. Perception of diabetes severity varied immensely between the person with diabetes and healthcare professionals. This affected the way the condition was then approached.

rather than taking notes. As study leave was not granted for this piece of research, a professional transcribing service was employed so that the author's available time could be used to analyse the data. After the first three interviews the transcripts were reviewed by the study supervisor. It was recommended that more open questions be asked and the issues raised by the participants explored in more detail. This would provide further information about how diabetes had impacted upon the different aspects of their lives.

Once conducted and transcribed the interviews were coded to link similar themes together using a computer software package (ATLAS.ti, Berlin, Germany). These themes were also reviewed by the supervisor and then amended so that the coding was effective in retrieving the relevant data. Having coded all the interviews and reread all the transcripts to more fully grasp each individual's perspective more accurately, the author analysed the data to draw together key themes and concepts.

Results

Initially, 60 individuals between the ages of 45 and 60 years were invited by letter to take part, with 16 responding positively (less than the one in three positive responses anticipated). When the inclusion criteria were adjusted to include people aged 40–60 years, 10 more were invited but there were no respondents. Finally, the age for inclusion was raised to 40–65 years, resulting in eight more responses of which six were interviewed (two could not be contacted by phone to arrange the interview). In total, 22 interviews took place; however one could not be used for the purpose of this research as it transpired this individual's diagnosis with diabetes had been made more than 10 years earlier, which was outside the scope of this study.

The average age of the remaining 21 participants was 57.5 years and the average time since diagnosis was 3.5 years (range 3 months to 9 years). Thirty-three per cent (n=7) were female.

A number of key themes emerged through the interview process and developed as the data were analysed.

The relationship with the healthcare professionals affects adherence to management plan

A good relationship with the healthcare professional appeared to mean that individuals would try to follow the advice given because they understood that this would improve their health outcomes. If they were treated more as individuals and were not rushed through appointments they felt more eager to listen to and follow recommendations.

'I think that she's amazing, lovely, caring; she'll warn you about this and say not to do that.'

(Male, aged 60 years, 8 years since diagnosis)

'The fact that the doctor takes the issue of diabetes so seriously means I make the assumption that if they're prepared to put what must be some of their resources into keeping it under control, I have to take it seriously as well.'

(Male, aged 57 years, 2 years since diagnosis)

Several interviewees felt the clinics were too rushed and that they were prescribed medications to control their blood glucose levels because that was an easier option than being encouraged to improve their diet or activity levels. A few interviewees also reported that the healthcare professional would reprimand them for not following advice and did not always seem sympathetic to difficulties relating to personal circumstances. One interviewee felt that, in his experience, patients were generally treated as idiots.

Perception of diabetes affects adherence to management plan

Perception of diabetes severity varied immensely between the person with diabetes and the healthcare professionals. This affected the way the condition was then approached.

'Yes, well, if you don't look after yourself, your feet drop off and you go blind, so there's

*quite an incentive to look after yourself.
(Female, aged 55 years, 6 months since diagnosis)*

*'But in the – let's say – scale of diabetic seriousness, I'm at the low end.'
(Male, aged 64 years, 2 years since diagnosis)*

Established health beliefs affect the way individuals respond to their diagnosis

Some of the individuals participating in the study believed that they were 'illness victims' and nothing they could do would exert any control over their health outcomes. One individual believed that her lifestyle was completely healthy and she could not understand why she had been afflicted with diabetes.

Others did grasp the seriousness of their condition and understood that by following a set of health recommendations they could reduce the risk of complications related to the condition. It was not just health beliefs but also the constraints of their daily lives that determined whether they felt they could follow given advice.

*It [diabetes] really is one of those illnesses, to a certain extent, that lays in your own hands. It's something that only you can really...not control... but really it is what you put in your mouth to a certain extent that decides how well your diabetes is controlled.'
(Female, aged 50 years, 6 years since diagnosis)*

*'Some people as you say can cope and some cannot. They think that if you talk about it, you are going to lose your – what do you call it? I don't know – people will look down on you. I don't think so; people will respect you more if they know what you have got.'
(Female, aged 57 years, 6 years since diagnosis)*

Disparity exists in the understanding of diet and exercise

The importance of diet and exercise in helping to control blood glucose levels was not fully grasped by all participants.

Inadequate education may have been given by

the healthcare professional or the information conveyed poorly. Conversely, there is disparity between the person with diabetes' view and that of the healthcare professional of the severity of the condition: some participants admitted that they might take the issue of their diabetes more seriously if the risks relating to complications had been spelled out to them around the time of diagnosis and been provided with more information about the significance of lifestyle changes reducing the risk of these complications.

'The doctor saying that you have got to lose weight, you have got to stop eating this and that you have to get your sugar levels under control. It's taken 4 or 5 years to really start hitting home.'

(Male, aged 46 years, 5 years since diagnosis)

'...but I can tell you something, they [the doctors] give you all these pills, but when my sugar level's high I can go outside and do half an hour's really hard work and it will be normal.'

(Male, aged 60 years, 3 years since diagnosis)

Discussion

In this study, one theme that recurred was that of the relationship between the person with diabetes and the GP or practice nurse. Additionally, the attitudes of the healthcare professionals had an impact on how individuals responded to any advice given or treatment recommended. Those who had not developed a positive working relationship with the healthcare professional often perceived their GP or nurse as being too busy – possibly too keen on ticking boxes and not interested in them as individuals. As a result, the person with diabetes felt less motivated to make changes to diet or lifestyle.

Where a good rapport was established the person with diabetes was motivated to try and change their lifestyle to see if what they had been advised actually made a difference. These individuals felt better empowered to care for themselves. Cooper et al's study (2003) also demonstrated this and showed that when certain individuals experienced 'integrity, respect and compassion' from their nurses this facilitated

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2. It was not just health beliefs but also the constraints of their daily lives that determined whether they felt they could follow given advice.
3. The importance of diet and exercise in helping to control blood glucose levels was not fully grasped by all participants.
4. Additionally, the attitudes of the healthcare professionals had an impact on how individuals responded to any advice given or treatment recommended.
5. If autonomous care is introduced by the healthcare professional people with diabetes become motivated to regulate their HbA_{1c} levels more carefully by making relevant lifestyle adjustments.

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1. Health beliefs may develop through a person's upbringing and the way their parents viewed health and illness.
2. By middle age, individual health beliefs are so well established that helping individuals to change presents a major challenge to the healthcare professionals.
3. Some of the interviewees admitted that it was only after regular education and fuller explanations that they began to understand the real dangers of diabetes and the necessity of trying to improve current behaviours.
4. An individual's perception of the importance of diet and lifestyle seemed to link quite closely with perceptions of disease severity.
5. A number believed that they had been given insufficient information about their condition or felt the reasoning behind the diet and lifestyle advice had not been adequately explained.

them in learning about their condition by asking relevant questions. Williams et al (1998) concluded similar findings in a study highlighting that if autonomous care is introduced by the healthcare professional people with diabetes become motivated to regulate their HbA_{1c} levels more carefully by making relevant lifestyle adjustments. People appeared to want time and interest from their GP or nurse in this study, but this was not necessarily age-related in any way.

Health beliefs affect response to diagnosis

Health beliefs may develop through a person's upbringing and the way their parents viewed health and illness. Several of those interviewed had developed their own set of health beliefs regarding diabetes from close experience with someone suffering from diabetes complications. This seemed to colour their response to diagnosis and make them determined not to suffer in the same way. One appeared devastated by her diagnosis because her lifestyle was apparently healthy and she had always seemed healthy. She found it difficult to believe she now had type 2 diabetes and wondered if there had been some mistake.

Some of the men interviewed had never needed to see their GP before their diagnosis as they thought themselves to be healthy: the diagnosis was one of their first visits to their GP surgery. This could perhaps have made the diagnosis harder to deal with. From these interviews and earlier research it is suggested that knowing about and understanding health beliefs could become a basis for negotiation with the person with diabetes concerning their individual treatment plan (Vermeire et al, 2001).

By middle age, individual health beliefs are so well established that helping individuals to change presents a major challenge to the healthcare professionals. It would perhaps be worth investigating further how to address this so that care can become more effectively patient-centred (Bodenheimer, 2005).

Patient perceptions of disease severity

In response to the way their diagnosis was presented to them, three or four participants felt their condition was easily dealt with and not a

major issue. A number viewed type 1 diabetes as the 'full blown' version of diabetes that is much more serious than type 2. This group then found it hard to understand how they really did need to change their diet and lifestyle because they were ignorant of the damage type 2 diabetes could cause. However, some understood from the outset the serious nature of type 2 diabetes and that as a result they needed to make changes to their lifestyle.

Clark and Hampson (2003) compared beliefs and attitudes between healthcare professionals and people with diabetes and also found quite a disparity between the two. It would seem that this issue needs to be addressed by the healthcare professional so that this difference can be minimised and the individual feel more empowered. Middle-aged people may have heard type 2 diabetes described as 'mild' in the past and it can be challenging to correct this way of thinking. Some of the interviewees admitted that it was only after regular education and fuller explanations that they began to understand the real dangers of diabetes and the necessity of trying to improve current behaviours. This too was recognised by Daniel and Messer (2002) in their work with Canadian Aborigines in British Columbia, although this was addressing people of all ages, not merely the middle-aged.

Perceptions of the importance of diet and lifestyle

In this study, an individual's perception of the importance of diet and lifestyle seemed to link quite closely with perceptions of disease severity. As the interviewees expressed a greater understanding of the former they were then able to grasp why they needed to alter eating and exercise behaviours.

In this study, a number believed that they had been given insufficient information about their condition or felt the reasoning behind the diet and lifestyle advice had not been adequately explained. This too is not a new finding; Frandsen and Kristensen (2002), in seeking to understand such perceptions, recognised this and how difficult it makes bringing about change in such individuals. This perception may well be related to the individual's health beliefs: if they see themselves

as a victim of disease they may not believe there is anything they can do to overcome or manage this condition.

In addition, individuals felt that when medications to assist with their blood glucose control were prescribed their own sense of responsibility diminished and motivation decreased.

One specific weakness of this study was the inability to obtain any realistic representation from those in their 40s. Those in their 40s were invited, but declined to respond. This could indicate the low importance they attribute to diabetes compared to work, family and other demands, which in turn highlights an issue to be addressed by healthcare professionals when dealing with people in this age group. Furthermore, as the majority of those with diabetes in their 40s and 50s are still working care provision for this age group needs to consider this. Perhaps care should be provided in a more flexible arrangement to overcome this potential problem – possibly early evening clinics could help – but this is an area which requires investigating if care is to become truly patient centred.

The aims of the study were achieved but only at a very limited level due to the small sample size. Therefore it would be useful to replicate this study in more sites to obtain outcomes that can be generalised across a much larger population of middle-aged people with type 2 diabetes. This larger sample could then be used to improve care provision for this sector of people and thus empower them more effectively.

Conclusion

The findings of this small study seemed to support earlier studies and did not reveal any factors which related particularly to the age of these participants. It confirmed that a good working relationship between the person with diabetes and their healthcare provider is vital to form a working partnership with a good level of trust. Health beliefs must be addressed if progress is to be made in engaging people with diabetes in 'self-empowerment' and the importance of diet and exercise must be emphasised from the outset as the cornerstone of effective type 2 diabetes

self-management. Further research could be conducted to discern how to change the health beliefs of people with diabetes and improve self-motivation, as there are a number of questions which at present are left unanswered. ■

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